

CONTENTS

Case Studies in Critical Care Medicine

Second Edition

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Preface ix

- 1 / Clinical Blood Gas Monitoring 1
Christina Chomka
- 2 / Monitoring Cardiovascular Dynamics 16
Barry A. Shapiro
- 3 / Detrimental Work of Breathing 30
Roy D. Cane
- 4 / Conventional Mechanical Ventilation 52
Barry A. Shapiro and Roy D. Cane
- 5 / Alternate Forms of Mechanical Ventilation 82
M. Christine Stock and Roy D. Cane
- 6 / Arrhythmias and Cardiac Failure 102
Richard Davison and Kerry Kaplan
- 7 / Nutritional Support of the Critically Ill Patient 115
Richard M. Vazquez
- 8 / Pain Control and Symptom Management in Critically Ill Patients 139
Donald M. Sinclair and Anthony Giambardino
- 9 / Drug Overdose 170
Roy D. Cane
- 10 / Smoke Inhalation 186
Paul S. Mennick
- 11 / Critical Care of Neurosurgical Patients 195
William T. Peruzzi and Tod B. Sloan
- 12 / Nontraumatic Coma 230
Jeffrey I. Frank and Scott L. Heller
- 13 / Pulmonary Aspiration 251
Jeffrey Vender
- 14 / Acute Renal Failure 266
Frank A. Krumholzky and Nancy A. Nora
- 15 / Acute Myocardial Ischemia 281
Dan Fintel and Kerry Kaplan
- 16 / Gram-Negative Bacteremia and Shock 299
Richard Davison
- 17 / Coagulopathies in the Critically Ill Patient 308
David Green and Benjamin Espanez
- 18 / Acute Lung Injury and Positive End-Expiratory Pressure Therapy 321
Barry A. Shapiro and Roy D. Cane
- 19 / Infection in the Immunocompromised Patient 347
John P. Phair
- 20 / Gastrointestinal Tract Bleeding and Liver Failure 362
Arvydas Vanagunas
- 21 / Chronic Obstructive Pulmonary Disease 381
Jeffrey Glassroth
- 22 / Acute Endocrine Emergencies 396
Mark Stolar
- 23 / Ethical Dilemmas in Critical Care Medicine 412
James F. Bremahan

23/ Ethical Dilemmas in Critical Care Medicine

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Other chapters in this book deal primarily with technical issues in critical care medicine. We turn now to troublesome human relations challenges, perplexities raised by differences of view among participants in medical decision making about the role of values in the practice of critical care medicine. We focus, then, on the effort to resolve ethical or moral dilemmas, and this for a very practical purpose, in order to achieve more effective patient care.

ETHICS IN CRITICAL CARE MEDICINE

Ethics in this medical context is nothing else than the effort of critical thinking to articulate "reasons why" some individuals affirm certain values very strongly and others, different values. Ethics aims, therefore, to explain how and why value conflicts arise about what to do. Better understanding of such conflict can often lead to mutually acceptable compromise in practice, if not always to agreement in principle. Ethical dialogue does not demand that any of the participants necessarily change their deeply held personal moral or ethical convictions. But it may enable more effective cooperation based on increased mutual understanding and respect.

Source Of Ethical Problems In Contemporary Clinical Medicine

Moral perplexity and dilemma in critical care medicine and thus the need for ethical reflection and discourse derive in our culture from two main sources: first, pluralism in the perception of and commitment to values on the part of the various participants and, second, the very complexity of the medical technology employed. These two sources more and more profoundly affect the human values' dimension of medical decisions that we cannot avoid making, especially in critical care medicine.

It is, first of all, important to recognize that moral dilemmas do not arise within a modern, culturally complex, and so morally pluralistic society because some participants in decision making are "evil," others "saintly." The need for ethical reflection on moral crises in critical care should not therefore be thought of as an exercise in moralistic "correction" of immorality, presumed or implied.

Complexity of Moral Pluralism

When we examine our varying experiences of value and our diverging interpretations of them, we find that people, care givers and patients, often agree that a particular value is truly "worthwhile" in shaping one's life, is truly important for decision making. However, we also find that in spite of such agreement at a very abstract, theoretical level, different people *prioritize* these shared values differently at another, more practical level where different values come into conflict with one another.

For instance, one person sees the primary value in the practice of critical care medicine to be *prolongation of biologic existence*. Another sees the controlling value in all medical practice to be *relief of human suffering*.^{1, 2} These contrasting perspectives on which value takes priority and overrides competing values in a situation where prolongation of life and relief of suffering are in tension with one another lead to conflict about decisions to be made. And the disagreement is more acute precisely when the decision to be made involves a life and death situation.

On the one hand, shared professional and cultural experiences make it possible for us to understand what another person means by asserting a particular value. Ethical dialogue is possible—we do not simply live in "different worlds" of value.³ But on the other hand, we can find ourselves puzzled, even put off, when confronted by the way a colleague gives a very different priority to shared values and so urges a very different resolution of a decisional challenge.

And yet, it can also happen that apparent theoretical agreement on values and their ranking will not necessarily produce agreement in practical application to a particular concrete situation. We can be surprised to find ourselves at odds with one another. Strangely too, we may often find that disagreement at a more theoretical level dissolves into agreement when we come to discuss practical cases together.⁴ Ethics as critical reason giving enables us to explore these possibilities more deeply rather than attempt to resolve conflict by unreasoning imposition of a leader's authority.

Ethical dialogue, therefore, should be practiced as a quest for understanding. Its outcome often cannot be predicted, and the benefit of our surprise may be both new mutual understanding and discovery of alternative ways of resolving apparently intractable disagreement on what to do next. Where this can be achieved, everyone involved will contribute more effectively to patient care.

The Search to Subject Medical Technology to Human Purposes

Many of our disagreements about what to do next and how to do it in critical care medicine are even more perplexing to us because we are constantly confronted with technologic innovation. This creates previously unsuspected possibilities for both benefit and harm to desperately ill patients. The very novelty of many of the technical issues to which the rest of this book is addressed means that over and over again we find ourselves unprepared for the moral dimension of a decision that cannot be avoided. The novelty of the case outdistances our comfortably customary convictions

3
about how to express moral values in medical diagnosis and treatment. And this kind of dilemma occurs widely in our high-technology culture, not in medical practice only.

Our ethical perplexity, therefore, is due not to some failure of moral fiber among modern medical care givers but rather to the success of our constantly advancing modern medicine in responding to acute crises.⁵ Our moral imagination is constantly challenged. And this is especially true in the practice of intensive care medicine. How do we deal appropriately with the approach of human dying in this context of constant technologic innovation?⁶ Our well-considered and customary answers frequently fail us. We have to think together anew about what we really intend, about how the new means we employ to achieve that intention may lead us to revise our understanding of the intention itself we thought was clear.

We perceive that our current skills and techniques of critical care can begin to fail, in some sense, to be effective in sustaining the humanity of patients. We encounter limit situations. Where patients cry out, "too much," we have to pause. Where "medical futility" in some sense becomes evident to one or another decision maker, we must take time to speak together of what we really intend and how we can achieve it.

Significant ethical perplexities can and do arise, of course, even during the more ordinary successful applications of techniques exemplified and described in earlier chapters. But, in this chapter we choose to deal with more dramatic situations—where death approaches—because these most vividly test our capacity for understanding one another's view of values and our ability to reconcile conflicting value concerns of all participants in decision making.^{7,8}

CASE STUDY 1: THE DYING PATIENT AND THE RELUCTANT ATTENDING PHYSICIAN

Mr. B., an 85-year-old retired business executive, has disseminated metastatic disease originating from prostatic cancer of 10 years' standing, as well as chronic obstructive pulmonary disease (COPD) and emphysema linked to a history of smoking. He is hospitalized from his home, where he resides with his wife, because of a pneumonia, and his fragile condition leads his attending physician of long standing, Dr. X.Y. to have him transferred to the intensive care unit (ICU). There, after consultation with the intensivists, it is proposed to Mr. B. by his physician that he be intubated and given support by a mechanical ventilator while antibiotic treatment continued.

Because Mr. B. is conscious and competent, before intubation Dr. X.Y. discusses with him the possibility, emphasized by consultants in the ICU, that should Mr. B. be intubated and placed on a ventilator, it might not be possible to wean him from it and return him to independent function. He is given to understand, as well, that this will probably also make impractical his return to life at home because his wife is not in good health and has shown confusion that suggests early signs of senility.

Mr. B. agrees to "try it." Mr. B. also agrees that a "do not resuscitate" (DNR) order be written that will forbid cardiac resuscitation beyond the use of pressors—should he experience life-threatening arrhythmias or cardiac arrest. He reiterates that he does not want full cardiopulmonary resuscitation (CPR), although he is willing to try the proposed intensive respiratory support.

Mr. B. is intubated and placed on the ventilator, and the regular course of antibiotic treatment of the pneumonia proves successful. But subsequently, careful and repeated efforts

over 3 weeks to wean him from the ventilator fail. Preparations are made to transfer him from the ICU to a floor where chronic ventilatory support could be continued, pending placement in a skilled nursing home.

Discussion

In this case and in contrast to what frequently occurs, a competent patient is explicitly informed about problems of treatment that his attending physician and the intensive care consultants foresee.^{9, 10} A relatively long-standing therapeutic alliance between the patient and his attending physician facilitates this. Awareness of the physician that there are burdens of treatment that the patient may well be unwilling to endure leads to maximum efforts from the beginning of intensive treatment to shape *reasonable goals of treatment* that respond to the patient's explanation of his hopes and desires for a continued life but only if burdens of treatment seem reasonable to him. Limits are set (limited "DNR") that appear to acknowledge this patient's own lifelong value commitments and that are sufficiently clear to be manageable by the ICU staff.

This would be desirable much more often in initiating intensive care treatment because the skills of intensivists in meeting minute-by-minute crises can sometimes obscure the overall aim or goal of these step-by-step interventions. Reasonable exercise of patient autonomy would then be impaired.

Dr. X.Y., Mr. B.'s attending physician, appears to agree to this experiment with intubation out of appropriate concern for wishes he believes his patient may have about limiting treatment and permitting death to occur, death now heralded by his fragile overall condition within the history of his declining health and advancing age.

This is not done because of Mr. B.'s chronologic age alone. That would raise questions about the *justice* of a decision to limit treatment, for instance, it might imply discriminating against the best interests of this aged patient because of concern for the best interests of other, younger patients who are making claim to resources being used to help him.^{11, 12}

Here the question of limited treatment is raised because of his general condition and his age. Indeed, this competent patient's own reservations about the extent of treatment, previously expressed to his attending physician before being hospitalized as his health status deteriorated, indicate his own judgment that the limits of treatment tolerable for him at his age and in his condition are about to be reached. A judgment about "quality of life" is not being imposed upon Mr. B. by Dr. X.Y. Mr. B. makes the judgment himself.¹³

Yet, Mr. B.'s consent to ventilatory support seems reluctant. He seems to imply, at least, that he may change his mind about how tolerable treatment on the ventilator will be for him. He expresses a conditional willingness to go along with what his physician, Dr. X.Y., proposes "for now."

So far, the mutual trust and understanding of a relatively long-standing doctor-patient relationship appears effective in shaping the ongoing medical responses to the patient's illness.¹⁴

Appropriate and *clinically realistic* consultation among specialists and with Mr. B.'s attending physician appears to focus very appropriately on the interconnection

between doubts about the success of the proposed treatment and the value commitments of this patient. Possible differences in perception and prioritization of values between care givers and Mr. B. are explicitly included in their critical care *clinical* analysis. Specifically, concern for the impact of "life-prolonging" treatment on the "quality of life" (which might produce "prolongation of dying," in Mr. B.'s view of it) demonstrates the appropriate concern of these professional care givers that their clinical judgment could become impaired by a "denial" of death and dying. They respond to Mr. B.'s awareness of the seriousness of his condition.

Also, appropriate resistance on the part of these care givers to the seductive impact of medical high technology and the aggressive action-oriented predispositions it can engender in them is also evident. This *patient's best interests* are being kept in the forefront of clinical judgment making at every moment. The DNR order does not prevent their aggressive technical response to his pneumonia and their willingness to help Mr. B. try out his ability to bear with intubation and treatment with the ventilator.

CASE STUDY 1 CONTINUED

Mr. B. is transferred from the ICU to a ventilator on the medical floor. After 10 days, Mr. B. communicates to his intern and to his nurses that he strongly desires to be removed from the ventilator. He shows too, what they interpret to be his clear although reluctant recognition that this will result in his dying. But, he writes, "This is too much to bear." When housestaff and nursing bring this up with Dr. X.Y., however, he expresses surprise and dismay—the patient has not communicated this to him at all. Moreover, Mr. B.'s wife appears confused about what Mr. B. is expressing to her and cannot make a clear decision when Dr. X.Y. brings this up with her.

Discussion

The agreement previously reached between Dr. X.Y. and Mr. B. included on Mr. B.'s part a proviso: "for now." Further investigation then might have revealed greater reluctance on the part of Mr. B. to undergo even initiation of ventilatory support in the ICU than was initially expressed by him or discerned by Dr. X.Y. and the ICU specialists. But, that "go ahead" satisfied Dr. X.Y. And, the ICU consultants assumed that an apparently more than usually nuanced understanding and agreement between patient and doctor existed. Now, Mr. B. has had well over a month of life on a ventilator, and he has been made aware that hope of weaning him has all but been eliminated. His real, time-tested experience of what this kind of living means to him, with his life goals and personal values, seems to be producing a wish for termination of treatment not really expected by Dr. X.Y.

Immediate care givers in constant and direct contact with Mr. B. are entrusted by him with a message that, apparently, he cannot give directly to his physician and that his wife in her present state cannot adequately grasp. These care givers remain open to hear his wishes and are concerned and ready to communicate it to Dr. X.Y. in spite of his reluctance to hear it.

From their interactions with Mr. B., these care givers appear convinced that Mr.

B. is not abnormally "depressed" (in a way that would be amenable to antipsychotic therapy), nor does Dr. X.Y. appear to think this is the case. Normal distress from enduring aggressive treatment and normal grief at the prospect of dying is accepted as inevitable and not usually psychologically disabling—not suicidal.¹⁵ The response of the housestaff and nurses to the value judgment of Mr. B. concerning the excessively burdensome nature of his present course of treatment, especially given his advanced age and his expressed realism about the inevitability of his now dying (his wish for the limited "DNR"), supports the judgment that he appears entirely competent and "reasonable".¹⁶

Dr. X.Y.'s consultation with Mrs. B., although not unusual and not in general inappropriate, suggests some reluctance on his part to confront Mr. B. himself about his expressed wish to be taken off the ventilator.

Family members are appropriately consulted to help interpret what they believe the patient means and wants, at least when real doubts exist on the part of care givers. They do not, however, have any moral or legal "rights" to control treatment against the expressed wishes of a competent patient and should not be allowed to interfere between patient and physician. They do, of course, have a need and therefore a right to be informed of the approach of dying of their loved one and to be helped by care givers to deal with their anticipatory grief. And most patients expect this help for their loved ones from their care givers.

Thus, although Dr. X.Y. cannot deny the reasonableness of his competent patient's request, it now appears that he has great personal difficulty in accepting the appropriateness of discontinuing aggressive treatment once begun—although he might, perhaps, have been ready to more readily accept a decision not to begin it. Mr. B. seems to be well aware of this, too, hence his reticence with Dr. X.Y.

It is not unusual for patients to be solicitous of their physician's real although not directly expressed convictions and wishes and to act in a way that avoids provoking even the possibility of "abandonment" by their doctor, and this even though the particular physician does not even remotely hint at this and would never in fact do such a thing. This is particularly the case with dying patients who greatly fear a loss of support.

CASE STUDY 1 CONTINUED

The housestaff and nurses persuade Dr. X.Y. to request an "ethics consultation" from the Medical Staff Ethics Committee (which is available for that purpose only at the request of the attending physician). A panel of four persons appointed by the physician chair of this committee reviews the chart, speaks with Mr. B.'s immediate care givers, and then, with the explicit permission of Dr. X.Y., interviews Mr. B.

To the committee panel Mr. B. communicates in writing his deep respect and affection for Dr. X.Y., but also his perception that Dr. X.Y. really does not believe in stopping ventilatory support, which will result in Mr. B.'s dying. "He's full of ethics," writes Mr. B., smiling wryly. "But there are things worse than dying," Mr. B. writes with tears in his eyes. Further, Mr. B. writes that he fears to experience distress in breathing, that he desires to die in his sleep. He even writes that he would want "the big pill" that will let him die now without distress.

Mr. B. is reassured by the committee panel that his wish to be taken off the ventilator will be communicated to Dr. X.Y. and respected by him. The committee stresses above all

7
that Mr. B. will be carefully and adequately medicated to prevent the distress and suffering he fears. The committee panel's physician chair communicates all of this to Dr. X.Y., and he accepts this account of his patient's wishes. He indicates, as well, his willingness to follow Mr. B.'s wishes. A patient care conference with the other care givers fills them in on these developments.

Mr. B. is brought back to the ICU at the request of Dr. X.Y., prepared with appropriate and adequate administration of sedatives, is taken off the ventilator, and is then extubated.

Mr. B. does not die immediately, and after a day is returned from the ICU to the regular floor and to the intern and nurses who have been taking care of him. With continued consultation of respiratory care he is kept comfortable with oxygen and analgesics, and he dies 48 hours later.

Discussion

In this case, the consultation, agreed to by the attending physician who was puzzled and upset about what other immediate care givers report his patient had expressed, resulted in increased mutual understanding among all participants. The Medical Staff Ethics Committee did not impose a treatment plan on Dr. X.Y.; it confirmed to Dr. X.Y. the wishes of his patient reported by other care givers and at the same time reassured Mr. B. that what he was reluctant to express emphatically to his doctor had now been understood by Dr. X.Y. Dr. X.Y. retained primary responsibility for the decision but was given reassurance both that it was what Mr. B. wanted and that Mr. B. was not making an unreasonable request.

So finally, all agreed on a course of action. When the previously unarticulated conflict about the ethics of intensive treatment as death approaches was "out in the open," Mr. B. and Dr. X.Y. had a new basis for going forward toward a more precisely defined ultimate goal of treatment—"appropriate care of the dying." The other care givers were also fully informed and confirmed as well in their sense of having served both Mr. B. and Dr. X.Y. in this difficult moment.

A factor possibly clouding achievement of agreement is the request of Mr. B. for the "big pill" that would let him die in his sleep. Is this a request on his part for "euthanasia" (in the sense of "active euthanasia" by care givers), and does any particular care giver's agreement to remove ventilatory support and to administer adequate medication for comfort thereby become participation in the patient's suicide and, in effect, homicidal?

In these circumstances of prolonged and stressful aggressive intensive care treatment, Mr. B. made an oblique suggestion ("a big pill") that something amounting to "active euthanasia" would be acceptable to him. Dr. X.Y. certainly seemed to oppose "active euthanasia" (understood to mean initiating a new lethal process to shorten the dying process, i.e., a lethal process distinct from and additional to the underlying disease processes that are causing Mr. B.'s demise). But the ethics consultants assured Dr. X.Y. that it was reasonable to interpret Mr. B.'s request to be for ending a treatment that he now perceived to be for him in his present circumstances *excessively burdensome*. Some would call this "passive euthanasia," but that need not deter Dr. X.Y. Such action ending what a patient judges excessively burdensome treatment has been declared to be morally acceptable by, among others, the Judicial Council of the American Medical Association.¹⁷ Such action is consistently protected by U.S.

courts from being punished as homicide or assisting suicide, at least where, as here, a conscious and competent patient requests it.^{18, 19}

After all, Mr. B. made this request that aggressive treatment now be ended after he had "given it a good try." Before his hospitalization, Mr. B. had already experienced the distress of air hunger as his COPD and emphysema worsened. It is not surprising that he feared a death gasping for breath. He was probably not aware of the medical capacity to titrate sedatives to ensure against such distress without deliberately aiming at death by overdose. So his words may be interpreted to indicate what he feared and to ask that it be forestalled.²⁰

One need not suspect suicidal ideation or depressive desperation on the patient's part under these circumstances. One can easily interpret his request as reasonable because it merely asks physicians to no longer intervene to prolong his inevitably proximate dying—a dying that, in his view, had begun long since but was unduly delayed by the application of these intensive therapies.

Readjustment of the treatment plan here to emphasize comfort of Mr. B. in his dying therefore prevented overemphasis on prolonging biologic existence and an unthinking aggressive response to each developing medical crisis that sometimes can distort clinical judgment. The traditional Hippocratic concern not to "do harm" by imposing "useless suffering" is brought to the forefront of attention and planning of therapy.

This responds to the rhetoric used by this patient whose words we may reasonably interpret to mean that he now wants desperately to make the simple point, "It's really time to stop now!" Thus, agreement by Dr. X.Y. not to continue respiratory support of Mr. B. need not be interpreted as an immoral and illegal participation in "active euthanasia" merely because the patient has spoken of a measure that might, ambiguously, suggest a readiness for active euthanasia.

If, however, Dr. X.Y.'s basic moral conviction is that biologic existence must always be prolonged by all medical means available, that no consideration of the patient's own judgment about his "quality of life" (even in the deep sense of intense suffering that cannot promise restoration of acceptable function) can justify withholding or withdrawing such treatment, then Dr. X.Y. should seek to transfer the final care of his patient to a physician who can accept Mr. B.'s, the other care givers' and the ethics committee panel's point of view. For in that case, deeply held moral convictions of the physician and of the patient would be hopelessly at odds with one another, and neither immoral compromise of the physician's sincerely held deep ethical commitment nor immoral compromise of the patient's sincerely moral autonomous request for cessation of treatment should be compromised.²¹

Pressures of "utilization review" simply to terminate or discharge Mr. B. were not reported in this case. Resources were not wasted, but rather Mr. B. was moved from the ICU to a medical floor, then back, and then to the floor again in response to real medical need. Mr. B. himself decided that further use of medical resources could not benefit him and asked for an end to their use. It is to be noted, however, that there exists no "DRG" for "dying" and yet that this course of treatment displays the need for sophisticated medicine in the service of pain control in a situation like Mr. B.'s.

An alternative approach might have been to transfer Mr. B. to a medically so-

phisticated "hospice" unit within the hospital.²² In this case, such a transfer did not become feasible until more than a year after Mr. B.'s death, when such a hospice unit was established.

CASE STUDY 2: A PERMANENTLY UNCONSCIOUS, THEREFORE NOW INCOMPETENT, DYING PATIENT WITHOUT FORMAL "ADVANCE DIRECTIVES"

Mr. F., an 85-year-old retired commodities broker, has essentially the same medical problems as Mr. B., but with the additional factor that brain metastases have resulted in his becoming comatose while at home, before being brought to the hospital.

He is admitted immediately through the emergency room and brought to the ICU. When the same Dr. X.Y., who is also Mr. F.'s attending physician of long standing, arrived, he is asked by the resident in charge whether Mr. F. has prepared either a "living will" or a "durable power of attorney" (giving another person authority to make health care decisions on his behalf should he become incompetent). Dr. X.Y. says that they have never discussed together what Mr. F. would want at the stage of terminal care, so he does not know. Therapy is begun (essentially the same as for Mr. B., above), and it includes intubation and a ventilator. Also, a neurology consultation is requested.

Mrs. F. arrived and says that although Mr. F. did not prepare anything in writing about this, he very emphatically expressed his wishes both to her and to their son and daughter and their spouses on several occasions over the past 5 years since his prostate cancer was first detected. She admits that he was reluctant to execute a formal advance directive or speak of this to Dr. X.Y. because he thought Dr. X.Y., on whom he felt dependent, might object. Mr. F., she says repeatedly asserted that he wanted to be allowed to "die peacefully" when "the end comes," without "being put on a machine," especially should he become unconscious. And Mr. F. was particularly concerned that costs of his final hospitalization not compromise the modestly sufficient investments on which Mrs. F. would depend for her support after he should die.

The son and daughter and their spouses arrive, speak independently with Dr. X.Y. and the ICU intern caring for Mr. F., and confirm exactly what Mrs. F. has said their father had told them about his wishes for limited care when, in the future, he would become terminal.

On the second day, a neurologist conducts a thorough examination of Mr. F., including electroencephalography (EEG), and after consulting with Mr. F.'s medical oncologist as well as Dr. X.Y. about the course of Mr. F.'s mental deterioration before this hospitalization, writes a note indicating her strong opinion that Mr. F. is not brain dead (because brain stem function continues) but has now entered a permanent vegetative state because of cortical impairment from metastases and that he cannot be expected to awake again to consciousness.

Both the neurologist and the medical oncologist orally expressed the opinion that Mr. F. might well continue in his present state for as much as a month or more if given aggressive support.

Mrs. F. and her children and their spouses meet with Dr. X.Y. and the ICU resident in charge on the third day and hear all of this information from them.

On the fourth day, they request of Dr. X.Y. that Mr. F. be extubated, be given whatever pain medication might be indicated to treat any residual capacity for pain he might have, and be allowed to die. They say that the ICU intern and nurse caring for Mr. F. discussed all of this with them and indicated they could make this request of Dr. X.Y.

Dr. X.Y. tells the ICU resident that he is reluctant to take this step, although he wishes he had not permitted Mr. F. to be intubated in the first place. He does not believe that Mrs. F. and the children are trying to entrap him into some kind of legal liability, but he also does not believe, personally and professionally, in stopping treatment once begun—at least not unless a patient, like Mr. B., is competent to tell him to do so. But, Dr. X. Y. agrees that no plans should be made to initiate medically engineered nutrition, whether by nasogastric tube,

by central line, or by percutaneous endoscopic gastrostomy. In a patient care conference attended by all ICU personnel who have contact with Mr. F., all immediate care givers, when informed by the ICU resident of these plans, agree that new intensive measures should not be instituted and that removal of the ventilator and extubation would be appropriate.

Dr. X.Y. wonders, however, whether the prosecuting attorney of the city, known to have ambition for higher office, may accuse him of homicide should word be passed about their discontinuing Mr. F.'s ventilatory support under these circumstances.

Discussion

An examination of the ethical considerations in this case should precede all discussion of legal problems that may arise. In fact, a clear understanding of the ethical issues will be the best grounds for whatever argument may have to be made to avoid or defend against legal complications—for instance, to deflect action by a prosecuting attorney or to forestall it by seeking legal guardianship of Mr. F. for purposes of making medical decisions on his behalf that insulate care givers and family from criminal indictment.²³

It should be noted, of course, that the execution of a living will in which the patient says what his wife and family testify to now, or better, appointment of a person other than his wife (whose financial interest might exclude her) with power of attorney that will survive the patient's becoming incompetent (if that is provided for in state law) would have prevented the concern of care givers (and, perhaps, family) about unwanted interference of the law in this situation.²⁴

From an ethical point of view, then, what Mr. F.'s wife and family testify to gives solid grounds for the care givers, including Dr. X.Y., to believe that Mr. F. would now want them to extubate him on the fourth or fifth day while providing as well whatever sedation seems reasonable to prevent his possibly experiencing any pain. His family emphasize what Mr. F. wanted rather than what they themselves want. They do not so much substitute their judgment for his as clarify what he himself would request if he could.

The medical situation of Mr. F., as it can be judged from the convergence of the various perspectives of his attending physician, Dr. X.Y., his oncologist, and the consulting neurologist, is grim. He is at the terminal or immediately preterminal stage of his disease (depending on how one defines these terms, the period of time a patient would be able to survive *without* treatment should be used to define "terminal"). Death is surely "near" for Mr. F. due to advanced and incurable disease.

And Mr. F. has entered a final stage of unconsciousness that excludes reasonable expectation of his awakening even temporarily to inform care givers personally of how much further attempt at cure he wants.

Mr. F.'s present condition, therefore, corresponds to his relatively long-standing expression of his value convictions about enduring continued strenuous treatment and about dying. He has not therefore mandated help with suicide but only limitation of "curative" treatment when it will be useless or unreasonably burdensome because it will merely prolong a dying process. It is implicit in that Mr. F. has indicated that mere biologic survival without a capacity for interaction with his family and friends is of no interest or benefit to him.

His family has heard him state this repeatedly over a period that precedes the metastatic involvement of the brain and any signs of dementia.

Although care givers may wish to exclude financial considerations from their own decision making in favor of what they understand to be the patient's best medical interests, the patient should be able to define his own best interests to include limiting expense of medical care. Many reasonable persons consider that an important factor in deciding to limit treatment because it is judged by them excessively burdensome.

The fact that Mr. F. does so here for his wife's sake should not disable her from testifying to his wishes (otherwise "Catch 22" results). And possibly suspicions about improper motives and possible misrepresentation by her are here laid to rest by the independent testimony of their children. No reasonable suspicions are raised here about their or his wife's possibly malicious motives.

While it is generally emotionally easier for physicians not to begin treatment than to terminate it once it has been begun, the basic decision is of the same kind in either case. Treatment that is no longer more beneficial than harmful to this patient, given his reasonable preferences, should not be begun or, if begun, should be stopped.^{25, 26}

The personal moral convictions of Dr. X.Y. may lead him to resign care to another physician who can follow Mr. F.'s wishes but should not lead him to oppose ending treatment. He admits he wishes he had not begun it. Dr. X.Y. would, of course, have to take more vigorous action to oppose ending treatment if he were really convinced that all other parties involved are unreasonable and/or bent on murderous harm to his patient.²⁷

The belief of some persons that whenever the digestive tract remains viable medically engineered feeding and hydration must be instituted and continued as "basic comfort care" is flatly contradicted by many reasonable people.²⁸ This results in two at least equally plausible views of moral obligation with respect to medical means of nutrition and hydration. There is, therefore, no moral obligation to institute such measures when the parties involved are convinced that this is medical treatment that would only prolong a "normal" or "natural" dying process.

The various communications between medical and nursing staff and the family do not appear to be aimed at undermining the authority of the attending physician, Dr. X.Y., but rather are good faith attempts to help Mrs. F. and the children understand the significance for them and Mr. F. of information being given them. Attempts to artificially restrict such good faith communication usually increase the possibility of misunderstanding and potential conflict.

It is generally undesirable that the decision-making process here be reviewed by a law court. Where all of the parties are agreed that dying would be prolonged, that further aggressive measures are excessively burdensome, appropriate compassionate care of the dying should be able to be provided without public interference.

At the foundation of the common law right to control one's medical treatment, and thus to refuse treatment unless there is a clear instance of suicidal action, there is very probably a constitutional right of privacy. And there is probably, as well, the specific constitutional right to free exercise of religion, to determine how one should deal with medical treatment in the all-important moment in living in which one

enters upon dying, and to do so according to each one's deepest convictions. The privacy involved in such "extralegal" decision making as these parties must undertake will therefore ultimately be protected by court decisions in most jurisdictions. Or at least where death is clearly near due to inexorably progressing disease processes, such basic human right to act without intervention of courts will generally be conceded by courts. Where the destructive disease process is slower, however, or where real doubts are raised about the true desires of the dying patient, some courts may be reluctant to grant permission to terminate treatment.

It seems both morally appropriate and also clinically desirable to fully explain to all care givers involved directly or indirectly with Mr. F. what is to be done and why. This prevents uninformed dissent, and so the danger of inappropriate intrusion by public officials in the care of this dying man is minimized.

CASE STUDY 2 CONTINUED

While discussion among care givers and family about whether and when to remove Mr. F. from the ventilator continues, on the sixth day in intensive care as Dr. X.Y.'s reluctance to take this step seems to wane, Mr. F. suffers a cardiac arrest. Continued use of pressors does not counteract this event, and in accord with the "DNR" order Mr. F. is not subjected to further cardiac stimulation.

Subsequent to his death no one contacts the prosecuting attorney. The family of Mr. F. expresses appreciation to Dr. X.Y. and to the staff of the ICU. Mrs. F. appears both grieved and relieved.

Mr. F.'s daughter and her spouse confide to one of the principal nurses who care for Mr. F. that they are convinced they must execute durable powers of attorney. They assert that they intend to discuss with their own internist their plans to avoid the difficulties in limiting treatment in a terminal care situation that they experienced with their father and Dr. X.Y. in order to be sure that their own doctor does not have this kind of reluctance.

Discussion

Not all outcomes are managed by family and care givers, especially in situations where death takes a hand in the game.

Preparation of effective advance directives by everyone likely to be cared for in the contemporary North American health care milieu demands consultation with persons likely to be involved as well as fulfillment of legal formalities of the living will or durable power of attorney.

CASE STUDY 3: A PERMANENTLY UNCONSCIOUS, THEREFORE NOW INCOMPETENT DYING PATIENT WHOSE WISHES ARE CLEAR BUT A RELATIVE OF WHOM IS IN DISSENT ABOUT FOLLOWING THOSE WISHES

Mr. H., an 87-year-old retired automobile dealer, also a patient of Dr. X.Y., is in substantially the same clinical situation as Mr. F. Also like Mr. F., Mr. H. has a wife and daughter who testify to his expressed wishes about limiting aggressive medical treatment when he should become terminally ill. But Mr. H. has a son who has been estranged from his father for many years. This son now appears in the ICU on the third day of his father's hospitalization

and hears all of the information about his clinical state and the testimony of his mother and sister about Mr. H.'s wishes.

On the fourth day this son states that he does not deny anything his mother and sister have said about his father's wishes. Nor does he doubt the accuracy of the collective judgment of Dr. X.Y., the medical oncologist, and the consulting neurologist that his father is now irreversibly dying and in a permanent vegetative state. This son insists, however, that he simply cannot and will not consent either to cessation of support by ventilator or to noninitiation of medical efforts to supply nutrition.

Mrs. H. and the daughter are greatly distressed. Dr. X.Y. is frankly afraid of being sued by the son or of being indicted by the prosecutor on the complaint of the son. The decision-making process completely stalls.

The immediate care givers, housestaff and nurses, are appalled at the aggressive measures now being continued and even to be added to. They view this virtually as medical torture that they must inflict on a fellow human being known not to want it and who is unconscious but may or may not have some vestigial experience of pain. At least, they insist to Dr. X.Y. and the attending chief of the ICU, this constitutes a meaningless and wasteful medical charade that demeans them and their profession.

Discussion

Some resolution of the son's problem is necessary for effective appropriate care of the dying father, Mr. H., along the lines recommended for Mr. F. Loyalty to his patient and fidelity to his patient's reasonable wishes is Dr. X.Y.'s (and also, all the other care givers') primary professional medical obligation, to be sure. But this son's apparently unreasonable, quite possibly guilt-ridden obstructionism cannot successfully be simply brushed aside, that is, his interference cannot be ignored without grave danger of making things even worse for the dying patient and for his wife and daughter.

This is one of the most distressing experiences that medical care givers can face.

Generally speaking, dying persons wish their care givers to take care of their family and loved ones, to help them through the stress of grief and loss. Seldom would a dying person simply demand that such needs be utterly ignored. Thus Dr. X.Y. and all doctors and nurses involved are implicitly empowered by the patient's probable implied wishes (in spite of his alienation from his son), as well as by the practical need to avoid probably grave interference with good care of this dying patient, to take all reasonable measures to help the son change his mind and consent to terminating treatment. This demands a combination of professional patience with imaginative approaches of every kind likely to help the son deal with his grief and anger in another, more fruitful way.

The intervention of liaison-consultation psychiatry may be of great help in fulfilling this obligation. Calling upon the consulting ethics committee, too, may open possibilities for helping the son to better understand what the medical situation of Mr. F. really is—a dying situation.

Only when such measures are seen to have failed and make recourse to a court of law inevitable in order to prevent a fully extended dying of Mr. H. should Dr. X.Y. and the other care givers strongly urge Mrs. H. to seek guardianship and explicit court authorization to order aggressive treatment of Mr. H. be terminated.

Of course, Dr. X.Y. and the other care givers should support Mrs. H. should she

seek court action sooner rather than later. Since her and her daughter's grief and, indeed, the son's grief, too, will be increased by adversary proceedings at law, this support, although firm, will have to be carefully modulated. It should continue to aim at helping the son change his mind.

Should the son be adamant but the wife and daughter finally be unwilling to seek guardianship to contradict his wishes but fulfil those of Mr. H., then Dr. X.Y. and the other care givers may be faced with the need themselves to seek court approval of a transfer of Mr. H. to another facility that may be willing to care for him. This would be their moral duty if it appeared to be the only way to break the impasse preventing appropriate care of Mr. H. in his dying. But in any case, the longer Mr. H.'s dying is prolonged, the greater the care that Dr. X.Y. and the other care givers must exercise to be sure that any possible awareness of suffering in Mr. H. is medically alleviated by appropriate use of sedatives.

CASE STUDY 3 CONTINUED

All efforts over 2 weeks to help Mr. H.'s son to recognize the inevitable dying of his father fail. Morale of the ICU nurses' and housestaff reaches a low point for the year. Dr. X.Y. consents to order modest doses of pain medication to ensure that Mr. H. is not aware of pain.

Mr. H.'s condition stabilizes, and he is transferred on ventilatory support to a medical floor. Turmoil builds on this unit as well but is contained by contracting for special extra nursing care for Mr. H. His family vacillates about legal action. Dr. X.Y. adopts a "wait-and-see" policy.

After another month, transfer of Mr. H. is successfully arranged to a public long-term care institution that accepts ventilator-dependent, permanently comatose patients—although with more limited personnel than are required in acute care hospitals. Three days after the transfer, Mr. H. dies.

Nothing more is heard from Mr. H.'s family.

With the help of the hospital lawyer, efforts are begun, involving both hospital administration and care givers, to interest the state legislature in a bill to establish nonjudicial procedures for resolving such disputes in the future, for instance, by empowering the spouse in consultation with the attending physician to determine to implement the expressed or implied wishes for termination of treatment of a now-incompetent patient against dissent of another family member. The state bar association convenes an interdisciplinary committee to draft such a statute, and a state legislator is found to sponsor it.

No immediate results of this initiative are reported.

Discussion

A struggle must be made to avoid resolution of problematic cases like this through what might be called "allowing to die by transfer." But an adequate consummation of this struggle requires that experienced care givers move out from the confines of the ICU and hospital, that they engage in efforts at advocacy within society, legislature, and law courts to change expectations and decisional procedures. The prevailing presumption in favor of continuing aggressive treatment must be given sane limits in situations where continued aggressive treatment aimed at "prolonging life" but in fact merely prolonging a dying process is unreasonably demanded at great

expense—both in human attrition and medical resources. Only experienced care givers can really inform and persuade people at large and political leaders to change this prevailing presumption.

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